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ABSTRACT

This informational document is intended to help answer questions commonly asked by families, professionals, and the general public concerning Down Syndrome. Medical problems associated with Down Syndrome include heart conditions, upper respiratory disorders, ear infections and hearing loss, vision/eye problems, cervical problems, and gastrointestinal anomalies. In Down Syndrome children, early cognitive development follows the same sequence as it does in nonhandicapped children (i.e., holding and mouthing objects, exploration and play, problem solving, imitation, concept development) but is delayed in most or all areas. Four areas of difference in language, hearing, and speech include different prelinguistic development, high incidence of middle ear pathology, and problems with incidental learning and generalization. Among general principles of motor development for Down Syndrome children are similar progression to that of all children, but slower rate and dependence upon others to avoid over exertion of the muscles. Self care skills including toileting and dressing are briefly considered as is social emotional development. A final section contains observations concerning older Down Syndrome children and adults. (DB)

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DOWN SYNDROME:

A CURRENT PERSPECTIVE

-BULLETIN 1762-

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INTRODUCTION

The information in this packet reflects the personal perspectives of Down Syndrome Project staff members in the various areas relating to children with Down Syndrome.

The information compiled in this packet is a result of working with children who have Down Syndrome and noting the most common questions asked by families, professionals, and the general public. This material is not a complete reference; rather, it is intended to be used as a response to frequently asked questions.

Please call the Down Syndrome Project at 504/342-1257 if you have any questions or need more information. The staff is available for technical assistance and inservice training at no cost.

MEDICAL PROBLEMS ASSOCIATED WITH DOWN SYNDROME

Although there are many medical conditions associated with Down Syndrome, too much emphasis is often placed on them. The significance of the medical conditions must be kept in perspective. The medical conditions presented in this packet are some of the most common in Down Syndrome and have a significant impact on development and education. Awareness of medical problems by parents and educators is very important, and a good medical management program is essential.

Heart Conditions

Heart defects occur in approximately 40 to 60 percent of persons with Down Syndrome. There are several defects which occur. Parents of children with a heart defect are well informed about the problem and are often a good source for information on specific disorders. The information below will briefly outline the structure of the heart and the problems which can arise.

The heart is made up of four chambers. The right side of the heart receives blood from the veins in the body and pushes it to the lungs where it receives oxygen. From the lungs, the blood flows to the left side of the heart and travels through the arteries to carry oxygen to the body. Structural defects may occur in the walls between the chambers, in the valves that control the flow of the blood, or in the position of the blood vessels. The flow of blood in the body while in the uterus bypasses the lungs. This system may fail to close at birth.

The treatment, if required, depends on the severity of the defect. Some may be treated with medication, others require surgery. Symptoms may occur immediately, or the condition may go undetected until signs of distress occur. Symptoms, depending on the defect, may be mild or severe: difficult breathing, blueness, poor appetite, slow weight gain, rapid pulse, and others.

Recommendations: Encourage the child to engage in age-appropriate activities. Increase the time alloted for feeding, etc. to prevent stress. If symptoms of stress such as increased difficulty in breathing, fatigue, blueness of lips or nails, or rapid pulse occur, the child should be allowed to rest.

Upper Respiratory Disorders

Upper respiratory problems occur frequently in most young children with Down Syndrome. The frequency does seem to decrease as the individual gets older. Conditions such as colds, sinusitis, bronchitis, and pneumonia are common. Some of these conditions may be chronic during the preschool years. There are many medications such as antibiotics, decongestants, and antihistimines which some physicians use to treat upper respiratory diseases.

Recommendations: Observe the children for symptoms such as coughing, runny eyes, congestion, and any nasal discharge which is thick and dark. Parents and teachers need to know the side effects of all medications, whether taken at school or at home.

Ear Infections, Hearing Loss

Because of the frequent respiratory problems, there is a high incidence of ear infections and hearing loss in persons with Down Syndrome. The infections can cause fluid to accumulate in the middle ear, which is located behind the tympanic membrane (ear drum). This fluid can cause pain and in some cases can rupture the tympanic membrane. Middle ear infections do not always have obvious symptoms. The most frequent treatments for ear infections are medications and surgical interventions. Small aeration tubes can be inserted into the tympanic membrane which may help with some audiological problems.

Hearing loss is reported in 70 to 90 percent of children with Down Syndrome. The hearing loss may occur only in conjunction with the presence of ear infections (intermittent) or it may be permanent. Most hearing losses in this population are reported as mild, conductive losses, meaning that the sounds do not travel through the middle ear cavity in the normal way. Any hearing loss can affect speech and language development.

Recommendations: Parents and educators need to be aware of the possibility of hearing problems. Good medical management and periodic hearing screening are necessary steps to managing hearing problems in children with Down Syndrome.

Vision/Eye Problems

Visual problems are reported in up to 50 percent of persons with Down Syndrome. Muscle imbalance occurs in 12 to 23 percent of the Down Syndrome population. The person's eyes may turn in (esotropia) or out (exotropia). Small rapid eye movements (nystagmus), occurs in approximately 15 percent of persons with Down Syndrome. Nystagmus is usually secondary to lens opacities and/or refractive errors. Refractive errors such as myopia (near-sightedness) or hyperopia (far-sightedness) occur in as many as 70 percent of individuals with Down Syndrome.

Treatments such as medications, surgery, and corrective lens are available. Periodic screening for vision problems is important. Vision problems can affect many areas of development and education.

Recommendations: Note any unusual eye occurrences and access appropriate medical personnel. Educators should be aware of diagnosed eye problems so that proper modifications in programming and teaching can be carried out.

Cervical Problems

A spinal condition, atlanto-axial dislocation, occurs in 12 to 17 percent of persons with Down Syndrome. This condition is also known as atlanto-axial sublaxation. In this condition there is increased movement of the first two cervical vertebrae. Children with this condition may not exhibit any symptoms; some, however, have gait problems. An injury to the neck of a person with atlanto-axial dislocation can result in paralysis and sometimes death.

Recommendation: Children who have atlanto-axial dislocation and in whom the condition has not been corrected should not engage in activities that could lead to cervical spine injury, such as contact sports, trampoline exercises, rough play, and somersaults. Routine physical examinations should include a check for abnormal neurological signs. Some medical authorities recommend cervical spine x-rays at the time when children begin physical play activities. This condition can be surgically corrected.

Gastrointestinal Anomalies

A significant number of children with Down Syndrome have malformations of the gastrointestinal tract (4 to 35 percent). Atresia (lack of an opening), or stenosis (narrowing) of the esophagus, stomach, or the small or large intestine may occur. Other disorders may involve the lining of the intestine, fistulas and twisting of the bowels.

Symptoms of the conditions may be present at birth, occur gradually, or suddenly as the child becomes older. Some of the signs of intestinal obstruction are vomiting, constipation, distention, and failure to gain weight.

Surgery is usually required.

Recommendations: Recognize and report changes in the child's eating habits, bowel and urinary output, and abdominal distention (tightness).

COGNITIVE DEVELOPMENT

Cognitive development for the young child can be described as the use of the senses and motor abilities for learning about the world. Children begin to learn and understand objects and events in their surroundings through observation, exploration, and interaction with the environment.

A young child begins the process of learning about the world by using the senses of sight, sound, touch, taste, and smell. Parents and teachers alike can stimulate this early cognitive development by providing opportunities for a variety of experiences. For example, moving the child to different rooms in the home or different areas of the classroom will give the child the opportunity to become familiar with different sights, sounds, tastes, and textures. Exploration of the environment is primarily through sensori-motor activities, that is, understanding that the world develops by moving around and using the five senses.

It is important for both parents and teachers to consistently monitor a child's vision and hearing. Without these two senses in proper working order, a child may be at a great disadvantage in interacting with the environment. Monitoring the child for problems at an early age may help prevent major problems in learning as the child gets older.

Early cognitive development can be divided into five areas. These areas do not develop independently of each other; however, each area does involve a sequence of skills. As children explore and act on things in their environment, they begin to build an understanding of the world around them. They learn about objects through play. The way a child relates to objects is an important area of early cognitive development. In this area, movement progresses from holding and mouthing objects to using objects in pretend play. The problem-solving area involves the methods of using the body or toys to help solve problems during exploration. For example, the child learns how to hold more than two toys and how to operate a mechanical toy. Object permanence involves the child's reacting to the presence or absence of people and things in the environment, such as a hidden toy.

Imitation is a fourth major area in cognitive development. A child learns many new skills by observing and copying others. As this skill is practiced and perfected, learning may take place much faster. A final area of early cognitive developent is pre-academic skills, or the development of concepts. In learning pre-academic skills such as matching and naming and selecting items, the child begins to put together many previous experiences and understandings to form concepts about the world. With practice on pre-academic skills, his movement progresses from a concrete understanding to a more symbolic or abstract understanding. At this later stage, the child develops an understanding of many concepts necessary for more formal learning, such as concepts of size, shape, colors, and numbers.

Early cognitive development can be enhanced by providing a variety of experiences for the young child. Play is the young child's best method of learning to think. Encouraging initiation of and involvement in play activities can help provide the stimulation for the proper sequence of skills in the development of learning.

In general, children with Down Syndrome have delays in most or all areas of development, including the cognitive area. However, the sequence in which each skill is attained follows closely with the sequence in which a non-handicapped child would attain the skill. The range of variability for the acquisition of certain skills in the cognitive area by children with Down Syndrome is great. This variability in skill levels of some children with Down Syndrome can be affected by associated conditions such as heart, vision, and hearing problems.

Children with Down Syndrome may have difficulty with the transfer from concrete to abstract methods of learning in the area of cognition. Children with Down Syndrome have also been reported as having difficulty with concept formation, with higher level integrative abilities, and with their ability to cognitively process environmental information adequately and appropriately.

One factor teachers and parents must always keep in mind when working with young children with Down Syndrome is that each child is a unique individual with his or her own learning style and abilities. Emphasis in programming should incorporate unique learning styles as well as rates of learning new skills. The goal of parents and teachers alike should be to help each child develop to the fullest potential through a warm, stimulating home and school environment.

LANGUAGE HEARING AND SPEECH

Most people are familiar with the idea that language and speech development will be delayed in children with Down Syndrome. The traditonal communication milestones (responding to sounds, responding to intonation, responding to commands, imitating sounds, using consistent sound combinations as words, naming pictures, etc.) will generally develop at a slower rate. Just as there are variances among nonhandicapped children in language and speech development, there are variances among children with Down Syndrome in their development. Not all children with Down Syndrome exhibit the same delays or the same differences. Instead of approaching communication in the traditional sense of delays, attend to these differences observed between children with Down Syndrome and other children:

A. Young children with Down Syndrome appear to go through the jargon stage of prelinguistic development differently. They may not babble or they may go from babbling to using true words, or they may stay in the jargon stage for a longer period of time.

Recommendations: Encourage each child to go through the normal stages of early language development, especially babbling and playing with the sounds of the child's language. These prerequisite stages are important. Enjoy these early attempts at communication. Encourage production of true words only after the child has had time to master several consonants and vowels and has played with them by stringing together pairs of them. Model (or say back) the true word when the child uses jargon to label or describe events in his environment. Acknowledge the child's attempt to communicate. Take advantage of the spontaneous use of language rather than demanding that the child "say" or "tell me" single words or words out of context.

B. Some 70 to 90 percent of children with Down Syndrome may show some form of middle ear pathology. Problems could be related to recurrent upper respiratory infections, congenital abnormalities of the ear and Eustachian tabe, and/or generalized muscular hypotonia.

Recommendations: Otological and audiological evaluations should be conducted before the child's first birthday and repeated on a regular basis. The importance of early detection (through otoscopic examination, typanometry, and puretone audiometry) and medical management cannot be overemphasized.

C. Children with Down Syndrome may have difficulty with incidental learning, with generalization, and with processing information. In the area of communication, these difficulties are reflected in the observations that children with Down Syndrome use little spontaneous speech or communicate experiences through language. It is also observed that delayed response time or inaccurate responses may be related to problems in processing what they have heard.

Recommendations: Structure the child's environment so that he/she has an opportunity and a need to communicate. Be careful not to predict or anticipate the child's needs. "Wait" - give the child a chance to process the information, resolve the conflict, obtain the desired object, or relate

the experience before you intervene. Provide visual as well as auditory clues when teaching.

D. Intelligibility is often poor for the child with Down Syndrome. Some children appear to use jargon for extended periods of time. Other children appear to lack the oral motor skills for adequate articulation. Some children appear to be aware that their communication attempts are unsuccessful; others do not appear to notice and do not attempt to change their verbal output.

Recommendations: Again, acknowledge the child's attempt to communicate. Model correct productions of words that the child may not be able to say clearly. If you cannot understand a child's message, look at the child's environment for contextual clues. Encourage the child to resolve this communication conflict, e.g. have the child point to what he/she wants, take you to the desired object, or use a sign or gesture for the object. Sign language in conjunction with the spoken word has been successful for many children with Down Syndrome. Often the child will sign the word, providing the listener with an additional clue for understanding. Articulation therapy may be recommended. Integration of the movements of the speech musculature may be delayed. More information needs to be obtained in this area.

MOTOR DEVELOPMENT

Motor development is the most obvious sign of growth and maturation in young children. Most parents and educators observe motor delays in a child's development before any other area of development. When teaching a child with Down Syndrome, the following general principles of motor development and learning should be used as a guide.

1. Motor development milestones usually appear in the same order for all children and are continuous regardless of a handicapping condition. Children with Down Syndrome follow the normal progression of motor development, but generally at a slower rate than do non-handicapped children. A typical example is a child with Down Syndrome learning to walk at two or three years of age, which is a skill generally learned at one to one and one-half years of age.

2. Specific motor skill development emerges from general motor skill ability. Included in this principle is acquisition of large muscle skills before small muscle skills. Gross motor skills are the foundation for fine motor skills. In children with Down Syndrome, sitting (trunk control) is necessary before cube stacking (arm and finger control).

3. Maturation of the nervous system must occur in order to perform motor tasks. Children only achieve levels of development when they are ready. Readiness in this instance is neurological. Children are able to crawl only after the nerve fibers used in the motor task of crawling have myelinated (become neurologically mature).

4. Motor development begins with the head (cephalo) and proceeds to the feet (caudal) and begins at the trunk (proximo) and moves to the fingers (distal). An example of this principle is found in a child's ability to control his head, neck, and shoulders for sitting before his hips, knees, fingers, and ankles for walking, as well as trunk control before hand and finger control. Normal development begins with both limbs together (bilateral) followed by both limbs on one side (unilateral) and finally movement of the opposite arm and leg together (cross-lateral).

5. Early reflexes must appear and then be integrated in order for voluntary muscle movement to develop. An example is the grasp reflex, which when integrated allows for voluntary release of objects. Children with Down Syndrome may a) exhibit a delay in the time at which a reflex enters their motor system, b) often have an extended period of time in the reflex, and c) most likely experience a lack of intensity of the refelx.

6. Non-handicapped children independently stop performing activities before over exertion of the muscle. Often children whose movements are initiated by someone else must depend upon the other person to stop the activity before over exertion of the muscles and allow sufficient time for recuperation and rest. This is important with children with Down Syndrome because many of them have other health problems which would be aggravated by over exertion.

7. Children involved in the process of learning are found to have periods when growth in certain areas will be slow because their mental energy and the environmental emphasis cause another area of growth to surge rapidly. For example, when a child begins walking, interest in communication may decrease. Once walking is fairly well developed, interest in communication will again surface.

Research shows that at least 90 percent and as much as 98 percent of children with Down Syndrome have less than normal muscle tone (hypotonia). Some effects of hypotonia are delayed motor development and extreme flexibility. This is very obvious in the hip joints. Because of the increased flexibility, children with Down Syndrome may be able to assume unusual body positions (such as "w" sitting, splits, and knees over head). These positions should not be encouraged. Poor stability of the joints affects all of the movements of the body. Instability along with poor muscle tone mandate that the person(s) working in the motor area start very early with a consistent developmental approach to teaching the muscles appropriate, efficient movements using the above-mentioned principles.

It has been found in approximately 12 to 17 percent of the population of persons with Down Syndrome that there is an abnormal alignment of the first cervical vertebrae (atlas) and the second cervical vertebrae (axis). This condition, called atlanto-axial dislocation, is diagnosed by x-ray and treatable with surgical fusion. Some cases of atlanto-axial dislocation can be suspected by observing symptoms such as deterioration of ambulatory skills, changes in neck posture and movement, neck pain, changes in bowel or bladder function, and weakness of any extremities. Caution must be taken in selecting activities because of the possibility of neck injury which could lead to paralysis or death. If atlanto-axial dislocation is diagnosed, the following activities should be avoided: gymnastics, diving, starting block entry and butterfly stroke in swimming, high jump, soccer, trampoline, and rough play where the cervical area could be injured.

Some general points to keep in mind:

a. Normal movement experiences provide a foundation for normal movement.

b. Only give the child the amount of support needed.

c. Programming and adaptive equipment should be designed to encourage independent functioning.

d. Incorporate developmental principles into daily care activities, e.g., lifting, feeding, dressing, etc.

e. Provide a wide range of developmental movement activities; children need to experience a variety of positions and movement every day.

f. If you don't permit an abnormal movement, you must provide the child with a more normal movement as a substitute.

g. Motor development activities should be coordinated with activities in other areas. Gains in social, self-help, cognitive, and communication skills should occur with progress in motor skills.

SELF-CARE SKILLS

Self-care or self-help skills refer to the child's ability to feed, dress, and toilet himself. The development of self-care skills is crucial to a child's overall social development and the basis for eventual independent or semi-independent living. For the non-handicapped child, self-care skills are viewed simply as a means to an end; that is, the development of skills follows a normal progression which the child picks up incidentally during the course of day-to-day living. Self-care skills are often developed to such a high degree of precision that a non-handicapped person no longer needs to think of them. For the child with Down Syndrome, however, self-care skills may be difficult to acquire and may often require sustained practice in order to be maintained. Maturation is an important factor in the development of self-care skills for a non-handicapped child as well as for the child with Down Syndrome. Before beginning to work on a particular skill, educators and parents would do well to consult a sequential scale of development to determine whether or not the child has acquired the necessary prerequisite skills.

The newborn infant with Down Syndrome may not stretch out his/her head for the breast or bottle, but rather be passive until the nipple is placed in his/her mouth. There may be a weakness of sucking movements and of swallowing for many. The feeding may be less than vigorous, leading to a too early weaning, for which the child may compensate by tongue and lip sucking. As the child grows older, feeding progresses from bottle to strained foods, strained to textured food, and textured to regular table food. Progress in acquiring feeding skills is contingent upon the child's oral motor functioning and is determined by the child's developmental rather than chronological age.

Toileting is a topic of concern to parents of non-handicapped as well as handicapped children. A great deal of literature has been written on this subject, and most experts agree that no child will be toilet trained until ready. The major developmental milestones of establishing bladder control, establishing bowel control, and establishing a regular toileting routine can be task-analyzed into smaller and smaller sequential steps depending upon the needs of the child. It is important for the parents and teachers to coordinate efforts in this area, as in any other area. Knowledge of when the child reaches each developmental milestone is necessary in order to know when to begin efforts in toilet training. This can eliminate much frustration for the teacher and parent and most especially for the child!

The operations involved in learning to dress and undress provide a rich opportunity for children and parents to engage in problem solving together. In the initial stages of learning, children with Down Syndrome will be frustrated if faced with complicated buttons or zippers that they are unable to operate (the same is true of a non-handicapped child). Adults, who accomplish dressing and undressing almost without thinking, often have difficulty breaking the task down into small steps. However, with a little effort the task can be broken down into steps which the child can accomplish without failure. Another good training technique for parents to use in teaching the child with Down Syndrome to dress and undress is "backward

chaining." This involves starting with the final result or product being taught and working backwards from that point. As with non-handicapped children, children with Down Syndrome will first begin to help with dressing and undressing, then begin to pull off items of clothing on their own. The child then progresses to learning to put on clothing and finally masters difficult fasteners such as buttons, zippers, and hooks. The training techniques previously mentioned are useful in teaching any of the dressing/undressing sequences. Because of the shorter fingers associated with Down Syndrome, these children may experience some difficulty in acquiring dressing skills, especially in mastering buttons, zippers, and hooks. Parents and teachers should exercise patience, be as encouraging as possible, and not press a child to master a task for which he is not maturationally ready.

In the area of self-care skills, the child with Down Syndrome should be encouraged to become as self reliant as possible. Assistance (oral and/or physical) should be reduced as the child gains independence. Practice in self-care skills may enhance communication as well as social and motor skills.

SOCIAL/EMOTIONAL DEVELOPMENT

The social/emotional characteristics of individuals with Down Syndrome have stereotypically been classified as cheerful and placid. Recent studies have suggested, however, that this population is no more homogenous than any other exceptional population, and thus does not fit into a predescribed mold of social/emotional behavior.

It is evident that the social/emotional development of the child with Down Syndrome is dependent upon several factors. Intellect, temperament, age, sex, and environmental conditions all have a profound effect upon social/emotional development.

The development of a child with Down Syndrome progresses through relatively the same social/emotional stages with little variance from that of any other child. The progression of the child through these stages, however, is determined by developmental level rather than chronological age.

Babies less than one year old are capable of expressing such adult-like emotions as joy, anger, fear, and happiness in response to a variety of stimuli. Early social experiences largely determine what sort of adults children will become. The child with Down Syndrome who is at a developmental social/emotional level of less than one year begins to learn to trust the world. Consistency, sameness of experience, and continuity all play a role in the acquisition of trust. Suspicion and fear are the byproducts of undependable, inconsistent, and unsafe experiences.

The child who is functioning socially between the ages of two and three years begins to develop a degree of independence. Appropriate interactions with parents and teachers who permit children to do what they are capable of at their own pace and in their own way fosters the emergence of independence.

Misunderstandings in communication may serve to complicate this pattern of development. It has been documented that the parents and teachers of young children with Down Syndrome have found that if they waited longer for the child to respond, more responses were noted. It is important to emphasize that not all children with Down Syndrome exhibit delays in response; however, it is of vital importance to allow the child with Down Syndrome to respond or act before assuming that he is not going to respond. It is also important to remember that this technique of interaction may require some practice before it is mastered, and that a certain level of frustration always accompanies the mastery of new skills.

The emergence of socialization occurs between the ages of three and six years. As with the child with Down Syndrome who is functioning at this social/emotional level, the number of contacts and quality of contacts with other children determines in part the progression of social development. A good preschool experience may help to increase the number and quality of social contacts with peers and may facilitate the social adjustment to future group settings.

Appropriate social behavior is important in children with handicaps at any age. It is extremely important as the child grows out of the preschool years toward adolescence. Socially unacceptable behaviors such as kissing and hugging strangers should be discouraged and appropriate behaviors should be fostered in home, school, and community environments.

BEYOND PRESCHOOL

Through middle and late childhood the individual with Down Syndrome will continue public school education in special classes or regular classes with resource help. Education in the academic areas continues. Training in daily living skills, such as dressing and grooming, and independent living skills, such as public safety and handling money, enables the individual to develop more independence. Adolescents and adults with Down Syndrome who are pursuing an independent life situation often participate in work-study programs. In a work-study program, students spend part of the day in the classroom and part of the day in on-the-job training. Sheltered workshop experiences provide work opportunities for individuals needing a controlled working environment. The work is usually subcontracted from businesses in the community. With early vocational/work experiences some individuals are later gainfully employed in their community.

The sequence of sexual development in individuals with Down Syndrome usually does not differ from that of their non-handicapped peers. Pubescence may be delayed, however. It is important that the adolescent with Down Syndrome be given direct and simple information about the physical changes in his/her body. Persons with Down Syndrome will have the same kinds of sexual feelings as their peers. With the help of understanding parents and teachers, the individual with Down Syndrome will learn socially appropriate ways to express those feelings. Females with Down Syndrome can become pregnant, and there is a 50 percent chance that the baby will have Down Syndrome. Little information is available regarding the fertility of males; moreover, there is no report in the literature of a male with Down Syndrome fathering a child.

The adult's leisure and recreation skills should be similar to those of other adults. Independence is not always easily attained, but it is typically a common goal for adults with Down Syndrome and their families. The life expectancy of adults with Down Syndrome has increased over the last several decades. Some individuals are now living into their sixties and seventies. Ongoing improvements in medical, educational, and social services should enable this trend to continue. This also means that many adults with Down Syndrome will outlive their parents. Living at home may be an option for some adults but other options are available, such as group homes in the community and independent apartment living.

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